

**REPORT TO THE TWENTY-FOURTH LEGISLATURE
STATE OF HAWAII
2008**

**PURSUANT TO SECTION 321-291, HAWAII REVISED STATUTES
REQUIRING THE DEPARTMENT OF HEALTH TO GIVE AN
ANNUAL FINANCIAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND**

**PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
OCTOBER 2007**

EXECUTIVE SUMMARY

The Hawaii Newborn Metabolic Screening Program (NBMSPP) is administered by Children with Special Health Needs Branch, Family Health Services Division, Hawaii State Department of Health. NBMSPP has statewide responsibilities for assuring that all infants born in the State of Hawaii are tested for phenylketonuria (PKU), congenital hypothyroidism, and other diseases that are added to the screening panel. This program tracks and follows up on infants to assure satisfactory testing and to assure that infants with the specified diseases are detected and provided with appropriate and timely treatment. The objectives are to prevent mental and growth retardation, severe health problems, and even death, resulting from disorders detectable through newborn metabolic screening.

In 1996, legislation was passed, H.R.S. §321-291, which established a newborn metabolic screening special fund which is used for operating expenditures, including, but not limited to, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

The Hawaii Administrative Rules, Chapter 11-143, revised and adopted on November 20, 2003, reflect the following changes:

- Expansion of the newborn metabolic screening testing battery to include tests for:
 - Phenylketonuria (PKU)
 - Congenital Hypothyroidism
 - Galactosemia
 - Hemoglobinopathies
 - Congenital Adrenal Hyperplasia (CAH)
 - Maple Syrup Urine Disease (MSUD)
 - Biotinidase Deficiency
 - Amino Acid Disorders
 - Fatty Acid Oxidation Disorders
 - Organic Acid Disorders
 - Urea Cycle Disorders

- Newborn screening fee increased from \$27.00 to \$47.00 per specimen collection kit beginning September 1, 2003. The fees are deposited in the newborn metabolic screening special fund, which pays for the following expenses:
 - Centralized laboratory testing for the thirty-one disorders. The Oregon State Public Health Laboratory was selected to be Hawaii's newborn screening testing laboratory after they were awarded the contract through a Request for Proposal process. None of the laboratories in Hawaii have the equipment or resources to do newborn screening testing.
 - Repeat testing for initial specimens collected at less than 24 hours of age
 - Confirmatory testing up to the point of diagnosis if specimens are sent to the designated testing laboratory
 - Specimen collection and handling
 - Overnight mailing costs of the initial specimens to the testing laboratory. Courier services must include tracking and overnight delivery capabilities to ensure that newborn screening specimens not be delayed, misplaced or lost. Timely screening tests performed on the newborn screening blood specimens are essential for early medical detection of thirty-one disorders that can cause mental and growth retardation, severe illness and even death, if not treated early in the newborn period.
 - Newborn Metabolic Screening Program staff salaries and fringe benefits
 - Hawaii Community Genetics for contracted Metabolic Clinic and Hemoglobinopathy Clinic follow-up services
 - Screening and diagnostic costs for the uninsured indigent
 - Tracking and follow-up, and the administration of the statewide newborn screening system
 - Continuing education
 - Educational materials
 - Quality assurance
 - Equipment
 - Indirect costs
 - Administrative overhead

On September 1, 2007, cystic fibrosis screening was added to the newborn screening panel. The Hawaii Administrative Rules, Chapter 11-143, will be revised to add cystic fibrosis to the list of disorders screened, and to increase the newborn screening fee from \$47 to \$55.

The attached financial report for FY 2007 (July 1, 2006 to June 30, 2007), required by § 321-291, HRS, identifies all fund balances, transfers, and expenditures made from the newborn metabolic screening special fund and the purposes for each expenditure.

PURPOSES FOR EXPENDITURES FOR FY 2007

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (3 FTE – includes salaries, overtime, differential, & fringe benefits for an RN V, Medical Technologist IV, & Clerk Typist II)	\$230,286.20
B.	Car Mileage	289.37
II.	Implementation of newborn screening system utilizing a centralized laboratory	
A.	Oregon State Public Health Laboratory	478,276.16
B.	FedEx services to deliver specimens to the testing laboratory	42,094.32
C.	Fax machine maintenance	363.68
D.	Dessicant packets and barrier bags	123.89
E.	Tyvek envelopes and office supplies	2,156.33
F.	Confetti-cut Shredder	171.60
G.	Laboratory services for the uninsured	340.00
III.	Continuing Education, Training, and Meetings	
A.	2007 Newborn Screening and Genetic Testing Symposium, Minneapolis, Minnesota, 5/5/07–5/11/07	1,294.30
B.	Registration fee for the ASCLS/CLMA Annual Meeting	180.00
C.	Subscription fee for PKU News	18.00
D.	Newborn Metabolic Screening training to nurses, physicians, and laboratory staff at Wilcox Memorial Hospital on 2/16/07	139.80
E.	Per diem for Metabolic Nutritionist for Neighbor Island Nutrition Clinics	180.00
F.	Air transportation for Neighbor Island Newborn Screening Advisory Committee members to attend Newborn Metabolic Screening Advisory Committee Meeting	1,955.35

IV.	Hemoglobinopathy Clinic services at Hawaii Community Genetics	25,000.00	
V.	Reimbursement of payment for indigent medical services	(62.50)	
	TOTAL		<u>\$782,806.50</u>

JV #JM4234 Assessments for central services and administrative expenses for FY 2006 \$56,176.96

BEGINNING ENCUMBRANCES FY 2008

Personnel	\$508.00	
Mileage	155.42	
Oregon State Public Health Laboratory	128,065.00	
Per diem for Neighbor Island travel	200.00	
Assessments for central services and administrative expenses for FY 2007	58,527.73	
	TOTAL	<u>\$187,456.15</u>

**Report on Non-General Fund Information
for Submittal to the 2008 Legislature**

Department: HEALTH

Date: September 27, 2007

Prepared by: Lucy Pascual

Phone: 586-4570

Name of Fund: Newborn Metabolic Screening Special Fund

Legal Authority: Section 321-291, HRS

Fund Type (MOF): B

Approp. Acct. No. S 302 H

Intended Purpose:

This fund is to be used for payment of its lawful operating expenditures, including, but not limited to laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

Current Program Activities:

The Newborn Metabolic Screening Program (NBMSF) has statewide responsibilities for assuring that infants born in the State of Hawaii are satisfactorily tested for 31 disorders which can cause mental and growth retardation and even death, if not detected and treated early in the newborn period. NBMSF tracks and follows-up on infants to assure that the infants with the specified diseases are detected and provided with appropriate and timely treatment. Other activities are assessment, quality assurance, continuing education, and standard setting.

Financial Data		
	FY 2007	FY 2008
Beginning Cash Balance	862,778.63	954,681.71
Beginning Encumbrances	215,574.58	187,456.15
Revenues	930,886.54	
Internal Transfers	0.00	
Expenditures	782,806.50	
Transfers (List Each Transfer by JV# and Date)		
JM4234, 03/28/07	56,176.96	
Net Total Transfers	56,176.96	
Amount Derived from Bond Proceeds		
Ending Cash Balance	954,681.71	
Amount Required for Bond Covenants as of 7/1/03		
Amount held in Certificates of Deposit, Escrow Accounts, or Other Investments as of 7/1/03		